



**COVARS white paper:  
From recognition to urgent action for long Covid Sufferers  
November 13, 2023, version**

Document produced by #ApresJ20 advocacy group.

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#ApresJ20 commends the white paper released on November 7<sup>th</sup> by the French Monitoring and Anticipation of Health Risks committee (*Comité de veille et d'anticipation des risques sanitaires*, COVARS), which acknowledges:

- the **lack of medical and social care** and **its harmful consequences** to the lives of **children, teens, and adults with Long Covid**,
- the need **to integrate patient expertise** into shared decision-making and the implementation of appropriate care structures and services,
- the **organic and physiological reality** of Covid Long disease, and the fact that it is absolutely not a functional somatic disorder,
- the importance of **intensifying national research** efforts.

The white paper recommends **comprehensive, multidisciplinary, long-term care throughout the country**, based on **empathetic and constructive exchanges**, to guarantee some prospect of **recovery**.

The goal of recovery in chronic diseases such as Long Covid is to help patients **develop their own strategies and resources** to live as well as possible with a disabling disease, and **to create a flexible environment** that can **adapt** to its evolution.

This comprehensive approach relies on the **training, coordination, and mobilization** of a network of players:

- **clinicians** to diagnose and monitor the patient,
- **social and psychological support professionals** to help sufferers with the legal, economic, social, professional, educational and / or psychological difficulties caused by Long Covid.

In this setting, psychological support is designed to help patients adjust to the changes brought about by their illness, while the illness itself does not have psychological causes.

Concerning the specialized Post-Infections Syndrome centers recommended by COVARS, we will ensure that **all the specificities of Long Covid are considered** in order to protect patients from stigma or worsening of their condition.

Moreover, we consider that the best name for this disease is the one chosen by patients and healthcare professionals alike, "**Long Covid**", as it speaks to the complexity of the condition.

Care should be **centered around pacing techniques** so sufferers can manage their energy and thus protect themselves from Post Effort Malaise or Post Effort Symptoms Exacerbation. This can be done through Therapeutic Patient Education programs that can be deployed on a large scale.

If patients are to be able to fully benefit from this method, it is essential **to raise awareness among employers and education professionals** so they make the accommodations that will allow Long Covid sufferers to keep working or pursue their education or, in the most severe cases, to facilitate access to disability pensions to guarantee an **inclusive society**.

French Public Health Agency Santé Publique France estimates that there are 2 millions adult sufferers in the country. COVARS **focuses** on the several hundreds of thousands who have the most serious cases and require multidisciplinary care. **We know that the epidemic hasn't gone away** and would like to remind everyone that the best protection against Long Covid is **to not be infected by SARS-CoV-2**, which requires the implementation of **protective and preventative measures** such as ventilation, air purification, mask wearing etc. and raising awareness regularly among health providers, patients and the wider public regarding the risks of Long Covid.

Finally, COVARS has acknowledged how **chaotic care** directed to Long Covid sufferers has been for the past four years. We hope that this time, **this white paper will mark a decisive turning point** in patient care. In a press release French Minister for Health and Prevention, Aurélien Rousseau, has promised he is “fully committed to providing a suitable response to patients”.

We address our warmest thanks to COVARS members for having listened our remarks and recommendations and for having taken many of them into account, and for acknowledging the role and expertise of patients in their white paper.

**It is now urgent to act.** These advances must now become translated into actions with and for the sufferers.

#ApresJ20 - Long Covid France Association - November 13, 2023